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ABSTRACT

This document presents the conference proceedings of the 1994 Joint Session of the Annual Project Directors Meeting for the Severe Disabilities Branch and the Office of Special Education Program's (OSEP's) Second State Coordinators of Severe Disabilities Networking Meeting held on November 7-9, 1994, in Washington, DC. The sessions focused on developing linkages, fostering collaboration, and encouraging networking among OSEP's funded programs in the area of severe disabilities; sharing and dissemination the latest knowledge that pertains to the education of students who have severe disabilities; improving educational services for students who have severe disabilities; and facilitating a nationwide environment that will lead to continuous improvement of those services. Presentations at the conference are summarized, including: (1) "Issues and Concerns from a Consumer's Perspective" (Hiram Zayas); (2) "Inclusion of Students with Interesting Behaviors" (Rob Horner); (3) "Inclusion--Your State Director's Perspective" (David Stockford and others); (4) "Problems and Successes with Public Schools" (Pearl Veesart), which examined parental attitudes toward and experiences with inclusion; and (5) "IDEA Reauthorization" (Patricia Guard and others). Concurrent presentations are also listed. An evaluation of the conference and a list of the participants are included. (CR)

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Proceedings of the 1994 Joint Session of the Annual Project Directors' Meeting for the Severe Disabilities Branch and OSEP's Second State Coordinators of Severe Disabilities Networking Meeting

November 7–9, 1994
Washington, DC

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I. Introduction

The Teaching Research Assistance to Children Experiencing Sensory Impairments Project (TRACES) and the Federal Resource Center for Special Education (FRC) facilitated a joint session of the Annual Meeting of the Project Directors for the Severe Disabilities Branch, and the Second Networking Meeting of the State Coordinators of Severe Disabilities, at the Omni Shoreham Hotel in Washington, DC, on November 7-9, 1994.

The Project Directors are funded out of OSEP's Severe Disabilities Branch, and direct special education projects funded in the areas of technical assistance, information and referral, dissemination, research, inservice, deaf- blind services, and state systems change.

The State Coordinators of Severe Disabilities work in education agencies in the fifty states to oversee the states' programs for students with severe disabilities.

Sponsored by the U.S. Department of Education's Office of Special Education Programs (OSEP), the purposes of the joint session were as follows:

Develop linkages, foster collaboration, and encourage networking among OSEP's funded programs in

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the area of severe disabilities.

Share and disseminate the latest knowledge that pertains to the education of students who have severe disabilities.

Through networking and sharing knowledge and ideas, improve educational services for students who have severe disabilities, and facilitate a nationwide environment that will lead to continuous improvement of those services.

TRACES and the FRC collaborated to organize this meeting.

II. General Sessions

General Session 1: Issues and Concerns from a Consumer's Perspective
Presented by Mr. Hiram Zayas
Monday, November 7, 1994

This general session introduced concerns about and issues pertaining to inclusion, and afforded the meeting participants a realistic view of the empowered role that people with disabilities can assume.

Mr. Zayas, a well-known businessman and, because of his life experiences, a strong proponent of inclusion, opened the conference by telling how his disability molded him as he grew up, remarking first on the disparity of people's reactions to his disability in the environments of home and school. He "had the privilege of experiencing segregation at school" but went home to parents who insisted that he join the local boys and girls' club, an environment in which there were no children with disabilities. Because of these experiences, he was thrust into an "inclusive" environment without the benefit of appropriate professional support.

Throughout his remarks, Zayas emphasized the importance of recognizing that different cultures view disabilities in different ways. He was born in Puerto Rico where, he said, many stereotypes exist about children with disabilities. While the special education system in Puerto Rico tried to cultivate self-reliance in Zayas, his parents wanted to take care of him. "At school," he said, "I was yelled at to become more independent. At home, I was yelled at for attempting independence."

Zayas emphasized the importance of working as a team in the special education field, and focused his presentation on the collaboration he envisions between people with disabilities and those without disabilities. He believes that when people with disabilities work alongside nondisabled people, those with disabilities are inspired to go beyond what they've been told their abilities are. For example, a person with severe mental retardation goes to the store with him on Fridays to reach items on the top shelf, and he goes to the bank with that person on Saturdays to help that person cash his paycheck. By working together, these two people with disabilities accomplish tasks that would otherwise prove extremely difficult.

Zayas spoke of the economic power of the disabilities community. For example, equipment and machinery intended to assist people with disabilities are also popular with people who have no disabilities but who "may be lazy" or "have a little extra money to spend," creating a broad market for the equipment and spreading innovative technology. He believes that people with disabilities should consider starting their own companies. Stressing the point that the disabilities community presents a formidable fiduciary presence, he mentioned the broad market for special clothing for people with disabilities (his own suits must be tailored to fit his body and are expensive, affording his tailor a hefty profit).

Within his own workplace, he tries to fill half his staffing needs with persons with disabilities. As a team, his staff bids on contracts to develop technology to assist disabled persons.

Education, said Zayas, creates job opportunities and mitigates prejudice. "If inclusion is facilitated appropriately, it's fine," he said. "Let's form partnerships: adults with disabilities; parents; providers. No

matter what the struggle is at the table of discussion, forming partnerships will result in better products." Zayas then asked special educators to better prepare their students for employment.

Frequently, Zayas impresses people with his own abilities, such as typing with his feet or using adaptive equipment to perform tasks seemingly impossible for him. He told a humorous anecdote about entering car rental agencies and, to the surprise of staff there, asking for a car. Incredulity is soon replaced by great interest as he outfits the car with adaptive equipment that allows him to drive, then drives away.

Zayas concluded his presentation by telling the special educators who were present that they "are no longer alone in trying to convince the world to take an interest in, and that there's power in, disabilities." He said, "We are not going to hurt people without disabilities by introducing disabilities to young people!" There are uncounted benefits, he said, to educating everyone about disabilities.

General Session 2: Inclusion of Students with Interesting Behaviors

Presented by Dr. Rob Horner, Professor of Education, University of Oregon
Tuesday, November 8, 1994

This general session discussed the issues that often arise in integrating diverse students into "regular education" classrooms, and made note of the fact that "the inclusion issue" is really an issue of understanding and accepting diversity.

Dr. Horner, an educator and researcher in the area of severe emotional disturbance and related issues, spoke in a general way about inclusion, then spoke particularly about children with emotional problems. He opened by saying that "the audience, the conference participants, are the ones who have defined what inclusion is, and the process we are using to make inclusion work."

Inclusion, said Horner, means much more than placement. He said that inclusion means "students with diversity" will be educated in the regular classroom in their neighborhood schools, and a natural proportion of diverse kids should be placed in all classrooms. Inclusion means turning all students into active contributors to their learning groups. "We also need to understand," he said, "the differences in inclusion on elementary, middle, and high school levels."

Inclusion is a process, said Horner, not an outcome, but inclusion should lead to certain outcomes:

Students should learn skills that increase their independence in academic, social, and personal routines

Students should develop and maintain social relationships.

Students should leave school with an adult role.

Inclusion is an effective way to develop social relationships. "We're learning that social relations are the core of effective education, and we're going to see research that shows the link between social relationships and effective education. Sometimes we put people in the position of choosing between skills and social relationships. This is a nefarious choice."

He noted some of the important lessons that people have learned from implementing inclusive practices. "We've learned that, in an effective education, kids teach other kids things that we can't teach them. That's really important. If we exclude access to peers, we exclude access to that teaching. There's teaching that goes on outside the lesson plans.

"We need to adapt traditional academic situations. Inclusion is extremely difficult in a thirty kid class with a lecture format. If we are going to include kids with diversity (not just disabilities), we need to spend time adapting curriculum, assessment, etc. This moves inclusion from a process that works for kids with disabilities to a process that works for all kids.

"Next, we've learned that inclusion is hollow if a student is unable to communicate with other children in

a setting. Students must be more than present; they must be communicating, interacting. Inclusion requires a fluid comfortable system of communicating with peers.

"And we've learned that if we're going to implement inclusion successfully, we need to focus on issues of mobility and community."

Noting that students with severely disruptive behaviors have made inclusion challenging, he told an anecdote about the process of including a particular first grader with challenging behavior into a regular classroom. Horner went to a school and was met by the principal, who led him to a class where the first grader was hitting his head against a wall and making squealing noises. The principal watched for a while and finally said, "Interesting. Please make that stop." Then the principal walked away. Clearly the principal felt the first grader's behavior did not belong in the class. He understood his political obligation to include kids with severe disabilities in his school, yet his action of bringing in an expert to "make the interesting behavior stop" indicated that his idea of inclusion was limited.

Horner showed a series of overhead projections detailing recent statistics about problem behaviors and students who exhibit them:

Three years after leaving school, 70% of antisocial youths have been arrested.

The stability of aggression over a decade is very high in this population, about the same as IQ: IQ=.70; Aggression=.80 (Walker, 1993).

More than 50% of all crime in US is committed by 5-7% of youth between the ages of 10-20 (APA Commission on Youth Violence, 1993).

Eighty-two percent of crimes are committed by people who dropped out of school (APA Commission on Youth Violence, 1993).

The three major factors responsible for increased violence in youth are (a) changes in family structure; (b) drugs and alcohol; and (c) easy access to weapons. Most of the weapons are obtained at home (Walker, 1993).

Approaches that are effective include: (a) social skills training; (b) curricular restructuring; (c) behavioral interventions (Lipsey, 1992). But these approaches are seldom used. Much more common approaches are punishments, such as suspensions and trips to the office. Punishing problem behaviors actually increases the frequency of the behaviors.

Exclusion and punishment are the most common responses to conduct disorder (Lane and Murakami, 1987).

Noting that regular educators view problem behaviors from a different perspective than that of special educators, Horner told the audience, "If we are going to advocate inclusion, we've got to understand the context within which regular educators deal with problem behaviors."

He presented data from a survey of 111 regular educators in Oregon to gain their opinion about teaching students with disabilities or problem behaviors (Bulgatz and O'Neill, 1994). The regular educators said:

Problem behavior in students is the primary concern of educators.

Frequent, low-intensity behaviors are as troublesome as high intensity behaviors.

Students with problem behaviors, in the teachers' view, reduce the quality of education for other students.

Teachers do not perceive themselves as successful or well-supported, yet are willing to keep trying.

Horner said that effective schools implement these two systems:

A school-wide system that defines the rules, then actually teaches the rules (which is unusual in schools), and provides regular feedback.

Specific setting systems: there is a specific time when, or place where, problem behaviors occur (such as getting on bus, or queuing up in the cafeteria). The way to defuse challenging behaviors is to forego individual intervention and look at the way in which the system operates. Eighty-five percent of behavioral problems that occur in specific settings exist with procedural structure. At one school students displayed problem behaviors during lunch. Part of the problem was that the school was releasing 400 or more kids to lunch through a single door. The solution was not to effect training in "walking through door" but to change the structure. By implementing these two systems, he said, 90-95% of problems can be eliminated or mitigated.

In summary, Horner stated his vision for making the process of inclusion work: "Inclusion is a dramatic and important event, extremely positive for kids with severe disabilities. However, if it's going to endure, it can't be something just for students with disabilities. It's got to be something that works for regular educators and administrators. We need to learn their language. We need to focus not just on individual students, but on building the capacity of schools, buildings, and districts to be effective for all children, not just those with disabilities."

General Session 3: Inclusion—Your State Director's Perspective

Presented by Dr. David Stockford, Director of Special Education, Maine; Dr. John Killoran, Education Specialist, Office of Education, Utah; Dr. Steven Johnson, Assistant Director of Special Education, California

Tuesday, November 8, 1994

The objective of this general session was to help participants answer the question: How might you be more effective in working with your state director's office?

First Speaker: Dr. David Stockford

Dr. Stockford began with a maxim: "Life is change, growth is optional; choose wisely."

Stockford focused his presentation on elements of a National Association of State Directors of Special Education (NASDSE) report, Leading and Managing for Performance: An Examination of Challenges Confronting Special Education (NASDSE, 1993). He quoted a passage from the foreword of the report:

"The future of our children and youth is the fundamental issue facing the country today. The way we respond to our children and their families is the strongest predictor of the future health and vitality of our society. Today, families must deal with issues that involve their children's health, education and general welfare. Systems to support children and their families are confronted with new challenges that rise from the need to provide a flexible array of supports sensitive to the diversity of our society."

Stockford pointed out the major initiatives and strategies that should be enlisted by educators:

Prevention through early intervention.

Inclusive schooling: "If we could get rid of the word 'inclusion' and focus on schooling or 'what we're going to do,' we'd move forward a lot faster."

School-based, school-linked health and social services: "This population of students requires extensive support."

Technology: "We need to recognize the unique needs of individuals and the technology that could allow them to participate in society as productive citizens."

New approaches to personnel preparation. "We are very dependent upon providers who don't have sufficient experience in looking at children with disabilities."

The identification of performance standards and assessment strategies. "We need to look at improving the results of the students we serve. We are preparing young people to compete in a global environment."

Working with regular education personnel is imperative if special educators are to succeed, said Stockford. He said that special education is a system of options provided to a student with disabilities to assist the student in meeting performance standards based on high expectations. "Special education is not a 'place,' and we should recognize that general education is not heaven."

Stockford reminded the audience of their responsibility to Goals 2000, and specifically mentioned Goal 6, which states, "All schools will be free of drugs and violence and offer a safe and orderly environment conducive to learning." He remarked that he felt too much attention has been devoted to establishing a connection between special education and violence, adding that special education students are often automatically assumed to be prone to violence.

Concluding his presentation, he told the audience, "It's your responsibility to make sure that 'systems change' in your state involves everyone."

Second Speaker: Dr. John Killoran

Dr. Killoran presented a perspective on inclusion from the Utah Department of Education, noting that while every state is unique, "there are common threads among states." He is not an inclusion advocate, he said, he's an "inclusion zealot."

"Inclusion is not a setting," Killoran said, "nor is it a placement. It's a belief. We hear that it doesn't work, because kids are dumped there. We need to work at effective inclusion."

Killoran discussed the value of inclusion and of the structure that has been built in Utah to achieve it. His presentation focused on examining the structure of the special education system, because "from firsthand experience, I know such an examination is needed if inclusion is to work." Early in his career he saw an integrated school — "a good one" — fail, because disabled and challenged students were placed in the school without support. The Utah Agenda for Meeting the Needs of Students with Disabilities guides education planning in Utah, and includes these items:

A Strategic Planning Committee that advocates inclusion and represents a collaborative team of principal stakeholders, including parents, regular educators, superintendents of school districts, and state legislators.

A set of belief statements based on inclusive values, the bent of which is that inclusion is not a disability issue but a diversity issue.

The Utah Agenda, said Killoran, includes several definite and necessary goals:

Achieve adequate, equitable funding for inclusive programs.

Design, implement, and evaluate an effective system of personnel development.

Use mass media to promote disability awareness among the general public.

Develop and implement a system of prevention, identification, and treatment of problem behaviors.

Develop a comprehensive system of providing access to integrated environments.

Develop a system for teaching social competence to students with disabilities or problem behaviors.

Killoran ended by saying, "We need to end the perception that special education is a special system. This was not the original intent (of special education). Special education was designed as an intervention. We intend to design education that is special for all students."

Third Speaker: Dr. Steven Johnson

Dr. Johnson said that any plan to develop "inclusive relationships" must consider the relationship of state personnel with others who are involved in the education of students. "It's up to us to model inclusiveness, to set the standard so that schools and educators have that support."

It is vital, he said, that funded special education projects maintain a strong link to state departments, and that relationships between projects and state departments are measured against how well they deliver services to families and children. He said that productive relationships between education stakeholders in California allow educators to align activities with the state agenda and with the department's issues, such as migrant education and bilingual education. "Projects benefit from the support of the state department, connecting with state standards and guidelines. Project staff have advance knowledge of regulations, policy, and guidelines. This gives project staff an opportunity to influence education procedures and assume the role of expert advisor."

Johnson stated that project staff are often featured in state documents and benefit from statewide exposure. The projects who get involved in statewide education efforts are remembered later and often called upon when issues within their area of expertise arise. This exposure "opens doors" for a project and raises the project in the esteem of others. "Projects benefit from the collaborative relationships that develop when the state lets them (the projects) in on state efforts," said Johnson. "The projects gain a voice."

Johnson identified the ways in which state education agencies benefit from relationships with special education projects:

- As projects go out in school districts on a daily basis, they provide SEAs with positive press among families and schools.

Projects provide the state with quick responses from families and schools.

There are drawbacks to the relationship, too. Project staff who are directly involved with state efforts may be required to pursue agendas that are contrary to project goals but which are important for maintaining a relationship with the state. Contrary agendas may also spark jealousy and infighting.

"Project staff and state department staff," concluded Johnson, "should keep each other informed, remember each other's needs (in contrast to an 'out of the room, out of the deal' mentality), and above all keep in mind the students who need their help."

General Session 4: Problems and Successes with Public Schools

Presented by: Ms. Pearl Veesart
Ms. Lisa Manfuso
Ms. Sue Ferguson
Tuesday, November 8, 1994

This general session examined parental attitudes toward and experiences with inclusion.

First Speaker: Ms. Sue Ferguson

"My own experience with inclusion?" said Ferguson. "My child's school system is doing a wonderful job dealing with inclusion at the elementary level. But the middle school and high school are still struggling with many facets of developing an inclusive environment."

Ferguson and her family live in a city of about 10,000 people. The city has established an autonomous school district. At one time, children in this city who were diagnosed with a cognitive disability were automatically "contracted out" to other counties. The local parents of children with disabilities didn't know each other well. Locally there were nine students with cognitive disabilities, attending nine different, extra-district schools. When a new superintendent and a new elementary school principal were hired, parents came together to talk about school recreational activities for their children. Through this incidental meeting the parents finally began to form a cohesive group within their city.

The parents, working with their school system, contacted systems change specialists at nearby George Mason University in Virginia and through the university's assistance learned how to lay the foundation for an inclusive program of education. They implemented an inclusive program based on a systems change model. "The real success of the program came from the fact that we took a full year to plan what to do with inclusion, following some of the aspects of the systems change model," said Ferguson. "It was never a matter of whether to do it or not, it was only a matter of what to do and how to do it." Administrative support makes all the difference, she said. "In our case, parents and school personnel formed committees to implement inservice, special accommodations, and other elements of an inclusive program."

Ferguson's child, Danna, is 11 years old and has Angelman's Syndrome. In her inclusive elementary school class, Danna was popular. Kids fought over who was going to help her, who was going to be her friend. Ferguson thought the attention would be shortlived, but it wasn't. In middle school Danna's classmates still fight over her, and Danna has boosted their self-esteem. Danna's teachers expect a lot from her. The standard of behavior set for the class applies fully to Danna. At the beginning of her inclusive education, she "sprawled all over the class and made disturbances," but now all the students try to "sit like Danna." Her receptive language has improved, and to communicate more effectively she utilizes assistive devices and pictures. The teachers and students with whom she learns are very creative and caring.

Of her daughter's successful inclusive education, Ferguson says, "We're once again members of the community. But we still need to be vigilant." Ferguson said that site teams disbanded when challenged students entered the school, as if inclusive education planning were no longer necessary. Ferguson reported that inclusive practices have not been adopted at the middle and high school levels in her city. She called for a city-wide site team to develop a mission and a vision for inclusion. "What to teach, where to teach it, and whom to teach it to are issues that still loom, particularly at the high school level," she said.

To parents who would advocate inclusive schooling, Ferguson advised, "Go slowly, plan thoroughly, get involved and stay involved in school governance, and don't plan to save any money."

Ms. Ferguson ended by telling the meeting participants how Department of Education Secretary Riley has released a document on family involvement in learning. This document is the research base for family involvement, and deals with the movement to get all families involved in their children's learning. "It is this kind of involvement," Ferguson said, "that will make inclusion work."

Second Speaker: Ms. Lisa Manfuso

Ms. Manfuso's son Mark was born prematurely, with detached retinas. At birth he developed a staph infection and the medicine that was given to him damaged his hearing.

Manfuso tried to locate resources to help her raise her deaf-blind (DB) son. "What should we do as parents?" Manfuso said. "We were alone, because very few people knew what to do.

"When Mark was two and a half, we thought it was in his best interest to send him to a school for the blind. He went every day, and when he was five or six we were told that it would be in his best interest to place him in a residential setting. So now he left us every Monday and came back Friday night. Sometimes he was so distraught that when I visited his school I was asked not to let him know I was there. I should have known this was a signal that something was wrong. But the school maintained his best interest, right? That's what I thought, but I began to feel like a failure, and saw my family unraveling."

As Mark turned 12, approaching puberty, his behavior worsened. He evinced head banging behavior, which residential staff didn't know how to handle.

"How do you think about the future when the past and the present are so horrible?" Manfuso said. "I knew if didn't do something for Mark, he was going to explode."

Manfuso contacted people who work with people who have deaf-blindness. They asked questions about what she wanted for Mark, but she had no vision for him. They encouraged her, respected her as a parent and individual, gave her programming suggestions, asked questions about the school district in which Mark was enrolled. "In this school district, 'inclusion' was a dirty word," she said.

Then they put her in touch with Joyce Ford, a DB specialist at DB-LINK, who asked more questions of her and "pointed out some things" to her. "Dare to dream, think beyond the current parameters, invent, create, do something, don't just sit there," Ford told Manfuso. "So," Manfuso said, "I began to dream, which was dangerous. I wanted everything for Mark that my other children had. He had no friends, no relationships, was always in the hands of an adult. I wanted him to have friends, to be with peers, to be able to go out into his community and be accepted, to have a job, to have a hobby, a source, an outlet."

Manfuso approached the county supervisor of special education and asked for a language facilitator. Previously, personnel at Mark's school had told her they couldn't afford a one-on-one facilitator for him. The supervisor agreed to help her, and she told the supervisor that she would pay for the facilitator as long as Mark could meet with the facilitator in Mark's home county.

Manfuso and the facilitator developed a daily plan for Mark that allowed him to interact with his peers. His residential placement ended in June, 1994. "He's up and running in middle school now," said Manfuso.

Every day Mark eats lunch with his friends "instead of eating in a cafeteria where everyone is self-stimulating" (i.e., producing self-stimulating behaviors such as banging a spoon or vocalizing repeatedly). He goes on school field trips, participates in activities, and has chores at home. He goes into his community to get his hair cut, to go trick or treating. He has a hobby now, making necklaces. He understands that "he has a sister, which he didn't know before;" now they play together and have fights as any siblings do.

Manfuso concluded her presentation with some very positive and hopeful remarks. "Mark has a well-rounded life now," she said, "and will continue to have a well-rounded life so long as he has the help of his friends."

Third Speaker: Ms. Pearl Veesart

Ms. Veesart began by saying that raising a daughter with a disability "has been a journey to the other side of shyness" to get at the "raw truth." Her daughter, Carina, is 13 years old, able-bodied, academically capable, proficient in American Sign Language (ASL), and has a full-time interpreter. Veesart said, "Carina has the heart of an artist — she's been drawing since could hold a pencil. She draws people together, shoulders touching, mothers with babies. In her deaf-blind world, she's created a people world. Her pictures are always about people and their connections to each other.

"She's fiery," Veesart said. "She's patient but she has spirit. She's been to the principal's office a lot. At

13. Carina is dealing with independence issues, as well as the interdependent (with an interpreter) and dependency issues of a deaf-blind person."

"We've experienced the full range of educational options," said Veesart, "starting with separate education. Then half-integrated education. Finally we investigated a residential campus. I spoke with a staff member there, who told me, 'Take your daughter home and fight like hell (for an inclusive environment).'" Veesart, a teacher herself, took Carina home. "I'm proud of my school and what I do, but my daughter has a home and nothing can replace that."

Veesart procured an IEE (Independent Educational Evaluation) for Carina, who began spending one half of each school day in a deaf program and the other half in a regular fourth grade class. But "the deaf program was horrible," said Veesart, who finally brought Carina to the neighborhood school.

Fifth grade was "pretty good" for Carina. Carina's teacher mandated that Carina's entire class get instruction in ASL from Carina's interpreter. Parents were excited because their kids were learning to sign, and began requesting their kids be placed in class with Carina.

In fall of 1994, when Carina entered sixth grade, "things took a turn for the worse." Leaving elementary school, she lost her technical assistance program, lost her interpreter, lost her education director, in fact lost everything that had been working for her. Building relationships with her assistors had taken years. Her interpreter at her middle school is not supported in any way by the school administration, is not a deaf-blind specialist, and there are "lots of problems between Carina and her." Without Veesart's knowing, Carina's translator kept Carina out of school. School staff knew before Veesart that Carina needed a new interpreter but did nothing to get her one. School staff did not think to consult Veesart to help Carina. Now, Carina is in school only 12 hours a week, and has no primary support teacher and no person with her at school who understands deaf-blindness.

"This is not to say that inclusion doesn't work," said Veesart. "This is an accountability issue for the schools. Schools needs to be multicultural; they need to fit together the deaf, deaf-blind, blind, and hearing and sighted communities."

Veesart recognized the importance of the interpreter's role. "Before you can talk about the programs we all know you're capable of implementing, you have to first talk about interpreters. Without an interpreter, nothing matters. The Federal government needs to make it a birthright that all deaf-blind kids have an interpreter and a teacher who has both training in teaching the deaf-blind and an understanding of inclusion.

"Carina," said Veesart, "needs a bold and innovative program. She requires an education. No one has questioned how much it cost or whether it was worth it to educate Helen Keller. I'm not saying my daughter is Helen Keller, but what worked for her will educate my daughter."

Veesart's conclusion was hopeful but stern. She said, "Inclusion is an issue of belonging. I believe in that parable about the mouse saving the lion's life. We have a recipe the rest of the world needs very much. We're not here just for our deaf-blind children, but we need to protect our identity and our children. We need interpreters, we need policies, we need a committee to look at interpreting issues. If you argue for your limitations, you get to keep them."

III. Lunchtime Speakers

During lunchtime of the first two days of the meeting, the assistant director of the Department of Education, and the director and assistant director of the Office of Special Education Programs, spoke to meeting participants about impending changes in the field of special education.

Lunchtime Topic I: IDEA Reauthorization
Speaker: Ms. Patricia Guard, Deputy Director, OSEP/DES
Monday, November 7, 1994

The text of Ms. Guard's speech:
When I met with you last year I provided an overview of the major education initiatives being proposed by President Clinton and Secretary Riley. I wanted to begin my remarks today with a status report of those initiatives.

We have seen significant achievements in putting a new education agenda in place. The President and the Congress have enacted a historic set of new laws. These are tools for states and communities to use in helping schools meet the challenges of the twenty-first century.

The Goals 2000: Educate America Act, which promotes higher standards for all students and encourages and supports local and state efforts to improve learning, teaching, and safety in schools, was signed by the President in March 1994.

The Improving America's Schools Act (formerly the Elementary and Secondary Education Act) was signed in October 1994. This act provides federal support for at-risk children to attain higher academic standards, greater involvement of parents and communities, improved teaching through better professional development, new assistance to make schools safer and drug-free, and support for effective changes in school practice and management, such as using technology to improve teaching and learning.

The School-to-Work Opportunities Act is helping communities and states put in place a high quality system of academic and occupational education to guarantee that every student leaves school with the knowledge, skills, and experience necessary for productive employment and further education. The President signed this into law in May 1994.

The Student Loan Reform Act streamlines the college student financial aid system by authorizing direct lending and income contingent payback systems to assure students access to high quality postsecondary education, regardless of their means.

With the reauthorization of the Office of Educational Research and Improvement, the Department's new system of research institutes will develop new knowledge for continuous improvement and make educational research useful and relevant to teachers, parents and principals.

These initiatives provide a framework and sound strategies for reauthorization of other key legislation next year, including the Individuals with Disabilities Education Act, the Vocational Education Act, and the Adult Education Act.

Before I talk about IDEA reauthorization, I want to spend a few minutes focusing on Goals 2000.

Goals 2000 is the centerpiece of and the framework for the restructuring of the American education system, based on eight National Goals. The restructuring effort focuses on high standards and expectations for all students, including students with disabilities, and emphasizes measurable achievement.

Currently 44 states have submitted planning grant applications, and the Department has approved 36. We expect all states to submit an application. These funds are to be used to develop each state's comprehensive improvement plan through a broad based panel comprised of legislators, state board members, teachers, principals, parents, representatives of business, of labor, and of higher education, and other members of the public. The statute indicates that the panel should be representative of the state with regard to race, ethnicity, gender and disability.

Goals 2000 represents a major opportunity for us to help create an educational system in which we have better results for all students, including students with disabilities.

Our IDEA reauthorization proposal will be developed within the Goals 2000 framework of challenging standards and comprehensive reform.

Let me outline the process for IDEA reauthorization.

We must have a bill passed by the Congress and signed by the President by September 30, 1995, or the discretionary programs will expire.

Although the reauthorization focuses on the discretionary programs, Part B has been amended in past reauthorizations and we expect that amendments will be considered this time.

The Select Education and Disability Rights Subcommittee in the House held hearings last Spring. They expect to hold a series of forums on specific topics in January and February 1995. The Republicans on the committee introduced a bill in August which sets up three priorities to improve the education for children with disabilities by amending sections of IDEA. These include: increasing student achievement and accountability; increasing parents' involvement in their children's education; and encouraging informal dispute resolution.

The amendments related to student achievement and accountability are directed to the definition of individual education programs (IEPs) and include, where appropriate, the addition of present levels of educational performance in the general education program as well as a statement of annual goals designed to help the child succeed in the general education program. In addition, there is a provision requiring a description for modifying services if the previous annual goals were not substantially achieved in the general education program. These revisions would occur at the beginning of the next school year.

The intent of this bill is to get the discussion going on specific topics that have surfaced during the past year. The House Republicans and Democrats on the disability Subcommittee typically work together to develop a consensus bill and I believe that is their intent this year.

The Senate plans to hold hearings when the Congress convenes next year.

We began the Administration's process for developing a reauthorization proposal last winter.

We believe IDEA is a good law and we want to use this reauthorization to make it better. We want to take what we have learned from the past nineteen years of implementation, and improve on it to ensure access to full educational opportunity for students with disabilities.

We are committed to an open process that will provide for meaningful input from consumers, educators, families, and the disabilities community.

We are actively seeking different points of view and we want the process to be one of collaboration and of seeking common ground within the disability constituencies and with the general education community.

Consistent with Goals 2000, we expect to make the law more outcome driven. To a large extent, this means raising our expectations so that we don't sell short the futures of the five million children and youth receiving special education services.

Secretary Riley spoke to this in his State of American Education Speech last February: "We must have a new ideal of American education grounded in the practical and hard-learned lessons of the last ten years. Categorizing and pulling out our children . . . telling them to just learn the minimum and to expect nothing more from themselves, led them to do just that. For too many of our children, we inadvertently created a tyranny of low expectations. We learned that excellence and equity are not compatible. Children respond to the expectations we hold for them."

We began the reauthorization process last December by holding eight outreach meetings. We invited representatives from national disability and general education organizations to share their views about the issues that should be considered during the reauthorization process.

Congressional staff members were invited to these outreach meetings. We wanted them to hear the same comments we heard. Out of these discussions, recurring themes emerged which pointed out areas that participants felt needed to be addressed. In the spring we then held another series of outreach meetings where we solicited from these groups suggestions for options to address the major issues that had emerged.

We held conference calls to get input on specific topics and we arranged for experts from across the country to meet with Secretary Riley and Deputy Secretary Kunin to help them explore these issues.

We also published the issues in the Federal Register asking the public for comment.

Through the Federal Interagency Coordinating Council, we held a public meeting on reauthorization of Part H and we have received recommendations from agency members of the FICC as well.

The fundamental objective of the Department's reauthorization effort is to improve results for students with disabilities in America's schools. Reaching this goal requires:

Aligning IDEA with State and local school reform efforts to ensure a system that enables children with disabilities to benefit from those efforts.

Preparing teachers and administrators to work more effectively with children and youth with disabilities in all educational settings.

Promoting the education of children with disabilities in the least restrictive environment and non-categorical approaches to services to better meet the needs of each child with a disability.

Improving the quality of educational services.

Focusing resources on teaching and learning.

Improving working relationships between parents and schools.

We have been discussing internally the major issues that have been raised and developing options and recommendations for Secretary Riley. While decisions have not been made yet, I want to share with you some of the major issues that have been identified and that we are discussing.

How can we align IDEA with Goals 2000, the School Improvement Act, and the standards and assessments employed by different states? How do we ensure that students with disabilities are appropriately included in states that challenge standards and the assessments aligned with those standards?

This is a critical issue. Over the past three years OSEP has funded the National Center for Educational Outcomes which has been studying the extent to which students with disabilities have been included in reform efforts.

The development of national standards in all core academic subjects is nearing completion and the National Assessment of Educational Progress which is regarded by many as the best method to gauge the success of school reform activities at the national level is already in place. The National Center for Educational Outcomes has found that nearly 50% of students with disabilities have been excluded from national assessments, and similar patterns of exclusion are prevalent in state-level assessments.

There has been much discussion about finance issues. Currently the Part B state grant funds are distributed on the basis of a child count which many believe creates an inappropriate incentive to label children and also may discourage states from undertaking reforms that would decrease the number of students to be served in special education even if such reforms would lead to better outcomes for children and services in less restrictive settings. Should the Part B state grant funds be distributed on the basis of a neutral factor such as population, rather than child count?

Many issues regarding categorization and labeling have been raised. Questions have been asked about whether changes should be implemented in the current eligibility requirements, including the use of 13 separate disability categories that would promote the education of children with disabilities in the least restrictive environment and noncategorical approaches that better meet the needs of each child.

We have heard concerns that categorical funding for special education has inhibited schools from fully integrating children with disabilities in school-based restructuring efforts. Categorical funds must be separately tracked and accounted for. The new School Improvement Act Title I funds for schoolwide projects in high poverty, Title I schools can be used in combination with formula grant funds provided to schools under all Department programs except IDEA. Schools must structure their school-wide projects to include children with disabilities. The issue of whether IDEA funds should be pooled with other federal funds in schoolwide projects was deferred to the IDEA reauthorization process.

We are considering if there are any improvements to the IEP provisions that would increase their effectiveness as tools for educational planning and that would better enable teachers and parents to help children to achieve high standards.

Relations between schools, and parents of children with disabilities, are too often adversarial. Without diminishing the rights and protections of children with disabilities and their parents, are there ways resolving disputes that are less time-consuming and adversarial?

Many concerns have been raised regarding the limitations on disciplining children with disabilities. Under IDEA, schools are prohibited from unilaterally excluding children with disabilities from the classroom for more than 10 days for dangerous or disruptive conduct arising from their disability. Suspension for more than ten days is considered a change in placement if the parents request a due process hearing. IDEA requires that no change in placement be undertaken pending completion of all administrative and judicial proceedings unless the parents agree to an interim placement.

This so-called "stay-put" provision was amended by the School Improvement Act that became law last month. The amendment provides discretion to school officials to remove any child with a disability who brings a weapon to school and place such child in an alternative educational setting for up to 45 days. If the parent objects or appeals to the courts, the child remains in the alternative placement and not in the original placement. This amendment sunsets on the date the reauthorization of IDEA is signed into law.

In preparation for consideration of this issue in IDEA reauthorization, the School Improvement Act directs the Secretary of Education to gather data on the incidence of children with disabilities engaging in life- threatening behavior or bringing weapons to school. The legislation also directs the Secretary to disseminate widely the existing discipline policies for students with disabilities with the present provisions for changing a student's placement if deemed necessary. Finally, the new law directs the Secretary to submit a report to Congress by January 31, 1995, analyzing the strengths and problems with the current approaches regarding disciplining children with disabilities.

We know that there are many students, particularly those in kindergarten through third grade, who have not been identified as disabled, but who are having learning or emotional difficulties that may lead them to being identified as disabled at a later date if they do not receive intervention in the early grades. As you know, the discrepancy formula for learning disabilities keeps many of those students from receiving services until they have reached third or sometimes fourth grade, even though research tells us that they could benefit from interventions much earlier. Should IDEA address this?

With the discretionary authorities, the Department is considering how it can improve the coherency and effectiveness of its discretionary programs. There are currently 14 separate discretionary programs authorized under parts C through G of IDEA. The programs are narrowly focused but overlapping and there is little consistency in authorized activities, terminology, target populations, eligible applicants, and funding requirements.

The program authorities make systemic approaches difficult or impossible. For example, the legislation

authorizes grants for statewide systems reform in the areas of transition from school to work and in severe disabilities but does not permit grants for more comprehensive approaches to systemic change.

There are significant gaps in current authorities. For example, model projects for learning disabilities are limited to children under eight years old; model projects for drop-out prevention are limited to students who are in high school or who are severely emotionally disturbed.

We are considering how resources from different programs can be consolidated or coordinated to address issues that cut across age ranges, disabling conditions, and types of activities.

Are there less categorical approaches that would better serve the needs of children with disabilities and their families?

We are particularly interested in determining how we can improve our technical assistance and professional development activities.

Professional development is the issue that has been raised most consistently through our outreach efforts. There is dissatisfaction with the current pre-service and in-service training of regular and special educators and administrators. We want to improve professional development of all teachers working with children with disabilities.

Are there changes in the law that would help to ensure that all teachers working with children with disabilities, including regular education teachers, have the training they need to help children with disabilities achieve to high standards?

The Comprehensive System of Personnel Development is often viewed by States as a significant paperwork burden that yields data of limited use to the states or to OSEP. Are there changes we could propose that would shift the focus of CSPDs to developing high quality pre-service and in-service that cuts across special education and regular education?

There are enormous resources provided in Goals 2000 and the School Improvement Act for these purposes. How can we link professional development in IDEA to overall efforts and to professional development in Goals 2000 and the School Improvement Act?

The School Improvement Act also includes significant resources for technical assistance. There are 15 regional technical assistance centers authorized. Are there ways to link IDEA with these centers to ensure that the needs of students with disabilities are addressed?

In the Part H program we have asked for comments about whether the current funding formula should be retained or changed, and if changed, how?

Should the number of children in poverty be a factor in allocating funds so that high-poverty areas receive a greater share of the funds?

And how can states be encouraged to serve at-risk infants and toddlers, and the families of these at-risk children?

We are in the process of sorting through the public comments we received from the Federal register. We have had many meetings with the Secretary and Deputy Secretary and we expect those meetings to continue until the Secretary makes decisions on the recommendations proposed by Assistant Secretary Judy Heumann and Undersecretary Mike Smith, who is co-chairing this process with Judy Heumann.

We expect to transmit the Administration's proposals to Congress by the end of January.

Our reauthorization process began with staff from across the department participating on working groups chaired by OSEP staff to develop issue papers with options and recommendations for consideration. What we have learned from our grantees such as yourselves informed the development of our proposals.

I hope those of you who had particular comments you wanted us to consider took the opportunity to submit comments to the Federal register or that you share them with your project officers.

We have much critical work to accomplish in the next few months and in the coming year. I'm pleased I had the opportunity to share our activities at the federal level with you. It is an exciting and challenging time to be involved in the education of students with disabilities in this country. We all share a common goal of improving results for children and youth with disabilities. We appreciate the work you do on behalf of students with disabilities and their families and we look forward to continuing our work with you as partners to make this goal of better results a reality.

Lunchtime Presentation II

Speakers Dr. Thomas Hehir, Director, OSEP
Ms. Judith Heumann, Assistant Secretary, U.S. Department of Education
Tuesday, November 8, 1994

During this presentation, the speakers limited their speaking time so that the audience would have time to speak. Ms. Heumann indicated that a microphone had been set up in the middle of the audience so that "you can share your thoughts and concerns and stories, and say what you think is working in your communities on a practical level, and what problems you believe exist."

Dr. Thomas Hehir

Dr. Hehir began by relating anecdotes of his experiences in classrooms that formed his philosophy about, and showed plainly the need for, inclusion. His experiences, Hehir said, remind him that "two decades ago, we may have thought inclusion was an unrealistic vision. He told the audience, "Many of you have worked tirelessly to make things better for students with disabilities, and people are increasingly assuming that all students are part of education and of communities." He noted that the Severe Disabilities Branch has been one of the chief catalysts of inclusive programs, and he said that inclusion is becoming the norm, although it is still controversial. "We have many places where students can be placed, because of your hard work. We have places in every state where people are succeeding in educating students with disabilities in inclusive environments." Hehir also mentioned the difficult and essential work of parents and families in moving toward integrated educational programs, saying of them, "You have been the cornerstone."

In his conclusion, Hehir stated, "As we become more successful, we become more controversial. As we start promoting effective inclusion, we come to the universal conclusion that we must restructure the way that education is delivered in this country, to include diverse students. Thank you for expanding what we know is best for our students."

Ms. Judith Heumann

Ms. Heumann began by saying, "I'm concerned about the growing negative message about disability related issues. The problems affecting disabled people will not be remedied with quick fixes. IDEA and Improving Schools are critical pieces of legislation, but they won't fix everything. We're in need of a revolution, we need an in-depth, systemic look at our society, because many people still do not understand that students with (and students without) severe disabilities can truly benefit from an inclusive education."

She went on, "The way we have thought about disabilities in the past is wrong. The families are the champions of the idea we are trying to create in this country: that people with disabilities can be equal members of society. What problems do you experience as you bring people with disabilities into inclusive settings? How do you help people overcome their fears?

"People say we are rushing to inclusion. We're not rushing. The legislation that introduces inclusion is over 20 years old. But people not involved in our work do see it as a rush. Realigning this view is one of the challenges we face.

"When we work with officials from the Department of Education who visit schools and see kids included in the primary grades, they doubt inclusion can be effective at middle and high school levels. We need to inform members of Congress, and the Secretary, about the successes of inclusive programs, not just the problems. The media doesn't provide the whole truth about inclusive programs.

"The progress toward inclusion is not rapid enough for any of us, but we don't want to turn back from the changes we have made. We need to bring constituencies together. Parents are skeptical, they don't like what they see their children getting in schools or how they themselves are treated by the school system. Groups need to come together to have dialogues, to produce legislation that is more aligned with school reform."

Heumann then said it was time to hear from the audience. She said again that she wanted to hear the "thoughts and concerns and stories" of conference participants, and opened up the microphone on the floor.

Parents and professionals came to the microphone to ask questions, most of which pertained to the reauthorization of IDEA and education in inclusive settings. The major issues of concern were categorical placement, the continuum of services, support for children in inclusive settings, and constituency building for successful change. The questions were direct and clearly stated. Many people in the audience had genuine concerns as to the manner in which their children, and all children with disabilities, would be affected by impending legislation and other administrative decisions. Other people were concerned about the movement toward inclusive settings. Assistant Secretary Heumann and Dr. Hehir displayed a keen awareness of and concern for the issues of which the audience spoke, and responded forthrightly to questions with the information they had at the time.

IV. Conference Evaluation Panel Presentation

At the end of the meeting, three professionals in the special education field formed an evaluation panel and presented some remarks on the content and proceedings of the meeting.

Panelists:
Dr. Clara Berg, Developmental Disabilities Center
Dr. Philip Bell
Dr. Harry Anderson

Wednesday, November 9, 1994

Clara Berg began the presentation by stating what she felt were the positive and the negative aspects of the conference:

Negative aspects
The length of the conference should have been two days instead of three, since participants have jobs and families to get back to.

Some of the concurrent sessions did not have many attendees, indicating a superfluity or overabundance of sessions, or perhaps audience lethargy.

TRACES should more freely share information about Federal activities that affect special education.

Positive aspects
The various projects attending the conference showed excellent communication and professional skills.

Berg said that each state should implement quality control panels to oversee special education projects. She said families should be heard alongside special education professionals, and that families and professionals must work together if the students under their care are to make progress.

Philip Bell's remarks centered on parental involvement in special education. He said:

Consumers (parents and students) are not often invited to share their thoughts on special education.

Technical assistance projects should involve parents more frequently and directly.

Parents and educators must work together.

Parents should not have to resort to litigation to get special education services. Bell suggested three ways to minimize the need for litigation:

1. Train parents to be better advocates.

2. Establish local educational advisory committees.

3. Include parents in special education decision-making processes.

Multicultural, socioeconomic, and ethnic issues were not addressed at the conference.

Bell said that attitude and support are crucial to inclusion. "Inclusion is a philosophy, and a right," he said. "A person has a right to be included."

Harry Anderson, a gentleman with deaf-blindness, spoke movingly on his experiences in the special education system as both teacher and consumer. He is the father of two sons, a teacher of the deaf and "a product" of the Minnesota School for the Deaf. Anderson suggested investing public monies in the private sector to augment those monies. He also remarked with regret that, among the parent representatives of children with disabilities, no fathers were represented.

Appendix 1: Concurrent Presentations

Sessions 1 and 6 of the concurrent presentations were times for special education projects and programs, divided by funding category, to meet and discuss common issues, concerns, and future activities. In sessions 2 through 5 of the concurrent presentations, professionals in the special education field presented the activities and plans of their projects or programs.

A. Concurrent Presentations, Session 1: Funding Programs
Monday, November 7, 1994, 10:15 a.m. - 12:00 p.m.

1. State/Multi-State 307.11 Projects
84.025A - State and Multi-State Services and Optional Pilot Projects for Deaf-Blind Children
Facilitated by Dr. Charles Freeman, Branch Chief, OSEP/DES & Dr. Vic Baldwin, Director, Teaching Research

2. State Coordinators for Severe Disabilities
Facilitated by Dr. Carol Valdivieso, Director, Federal Resource Center for Special Education
Dr. Dawn Hunter, School of Education, Chapman University
Dr. Richard Horne, Senior Program Officer, Disabilities Studies and Services Center; Deputy Director, National Information Center for Children and Youth with Disabilities
Ms. Debra Price-Ellingstad, Assistant Director, Federal Resource Center for Special Education
Mr. Thomas Justice, Management, Organizational, Education Consultant

3. Systems Change
84.086J - Statewide Systems Change
84.086V - Consortium on Inclusive Schooling Practices
Facilitated by Dr. Christine Salisbury, Allegheny Singer Research Institute
Dr. Ian Pumpian, San Diego State University
Dr. Beverly Rainforth, State University of New York-Binghamton
Dr. Mark Wolery, Allegheny Singer Research Institute

Dr. Virginia Roach, National Association of State Boards of Education

4. Technical Assistance
84.025C - Technical Assistance for Grantees under 34 CFR 307.11
84.025E - Technical Assistance for Transitional Services
84.025U - National Clearinghouse for Children with Deaf-Blindness
84.028A - Federal and Regional Resource Centers
84.1029T - Minority Outreach
84.030A - National Information Center for Children and Youth with Disabilities

Facilitated by Dr. John Reiman & Dr. Richard Zeller

5. Research
84.025R - Research in Social Relationships for Children and Youth with Deaf-Blindness
84.086A - Social Relationships Research Institute for Children and Youth with Severe Disabilities
84.086D - Innovations for Educating Children with Severe Disabilities Full-time in General Education Classrooms
86.025S - Research Validation and Implementation

Facilitated by Dr. Anne Smith

6. Practice
84.025D - Demonstration Projects for Children Who Are Deaf-Blind
84.086R - Model Inservice Training Projects
84.086U - Outreach: Serving Students with Severe Disabilities in Integrated Environments
Facilitated by Dr. Suzanne Martin

B. Concurrent Presentations, Session 2
Monday, November 7, 1994, 1:30 - 2:30 p.m.

1. Statewide Systems Change: GATEWAYS Model for Integration
Facilitated by Dr. Jeannine H. Brinkley, Director, GATEWAYS
The GATEWAYS project is a statewide training and technical assistance program designed to assist local school personnel to provide quality educational programs for students with severe disabilities in classroom and community settings in their neighborhood.

2. Disability and Disease: A School Administrator's Viewpoint
Facilitated by Dr. Pat Cooper, Executive Director, National Schools Health Education Coalition
This presentation discussed methods school administrators can use to address the needs of physically or mentally challenged students who have communicable diseases.

3. Educational Services for Students Who Are Seriously Emotionally Disturbed
Facilitated by Dr. Vicki Nishioka-Evans, Project Director, Teaching Research Integrated Service Program
This presentation described a classroom model serving students identified as seriously emotionally disturbed who have histories of emotional, physical and sexual abuse.

4. Teacher Work Groups: A Strategy for Helping Teachers Implement Best Practices
Facilitated by Dr. Dianne Ferguson, Associate Professor of Special Education, University of Oregon
This session described the results of a three-year project that helped teachers form work groups to implement school reforms.

5. DB-LINK Future Focus Forum: The 307.11 Program in the New Millennium
Facilitated by Dr. John W. Reiman, Director, DB-LINK
Dr. Michael Collins, Director, Hilton-Perkins National Project
Dr. Bud Fredericks, Director, TRACES Project
Dr. Dawn Hunter, School of Education, Chapman University

This presentation gave a vision of an idealized 307.11 Program, along with a realistic assessment of the present direction of the 307.11 Program. DB-LINK, the National Information Clearinghouse On Children Who Are Deaf-Blind, is a federally funded information network that identifies, coordinates, and disseminates information related to children and youth who are deaf-blind. The 307.11 Project refers to article 307.11 in the Code of Federal Regulations (34 CFR Ch. III, 7-1-93 Ed.), which allows financial assistance to "special education, early intervention, and related services, as well as vocational and transitional services, to children with deaf- blindness." (34 CFR Ch. III, p. 159.)

6. Louisiana Systems Change Project for Inclusive Education
Facilitated by Dr. Nanette Olivier, Supervisor, Severe Disabilities Programs, Louisiana Department of Education
Dr. William Sharpton, Professor, Department of Special Education and Habilitative Services, University of New Orleans
This session provided an overview of the Louisiana Systems Change Project, which emphasizes building the capacity of state and local education systems to support inclusive education.

C. Concurrent Presentations, Session 3
Tuesday, November 8, 1994, 11:15 a.m. - 12:15 p.m.

1. Project School Care: A Model for Bridging Transition
Facilitated by Dr. Timaree Bierle, Project School Care, Children's Hospital, Boston
Dr. Debra Hart, Institute for Community Inclusion, UAP, Children's Hospital, Boston
This session discussed Project School Care, a model for transitioning students with special health care needs into inclusive settings, using low-technology and no-technology assistive methods that promote independence, a positive self-image, and a capacity for positive social interactions in children with special health care needs.

2. Best Practices for Educating Students with Emotional Disturbance within Their Local School System
Facilitated by Dr. Ruth Walker Hamilton, Project Coordinator
This session gave an overview of the Best Practices for Educating Students with Emotional/Behavioral Disorders in their local school system. The presentation included a description of the manner in which these Best Practices support the student and his or her family and school.

3. Full Inclusion Program for Students Who Are Deaf-Blind
Facilitated by Dr. Lori Goetz, Professor and Director, California Research Institute
This session reported on initial outcomes of an effort to develop inclusive educational programs for students who are deaf-blind. The project focuses on curriculum development, delivery of specialized services, and social inclusion.

4. Systems Change in South Dakota
Facilitated by Dr. Phylis Graney, Model Systems Planner
This session presented some methods of changing educational systems, and discussed barriers that impede systems change.

5. Peers II California Outreach Project: Making Inclusion Work in Hard Times
Facilitated by Dr. Ann T. Halvorsen, CSUH Project Director and Regional Coordinator
This session discussed strategies for local systems change, effective service delivery, and replication of inclusive schools in eight California districts challenged by severe fiscal restraints. The session reviewed the project's work with more than 40 schools in urban and rural districts, including school level support strategies and methods to develop building-based technical assistance teams to match outreach efforts with schools.

6. Research on Social Relationships for Children and Youth with Severe Disabilities
Facilitated by Dr. Robert Horner, Professor, University of Oregon
This session presented research on the development and maintenance of social relationships by individuals with severe disabilities.

7. Social Relationships of Children and Adolescents with Deaf-Blindness
Facilitated by Dr. Harvey Mar, Project Director
This session presented strategies to enhance social relationships in children and adolescents who are deaf-blind. Several approaches were reviewed to address the needs of students in a wide range of educational settings.

8. Bumping Into Walls: A Strategy for Facilitating Durable Change
Facilitated by Dr. Jan Nisbet, Director, Institute on Disability, University of New Hampshire
New Hampshire is involved in a second phase of systems change that focuses on serious emotional disabilities, chronic illness, restructuring, higher education, and family support.

9. Evaluating Programs for People with Severe Communication Disabilities
Facilitated by Dr. Diane Paul-Brown, Director, Speech-Language Pathology Division, American Speech-Language-Hearing Association
This presentation gave information about two important products of the National Joint Committee on the Communication Needs of Persons with Severe Disabilities: (1) guidelines for delivering communication services to persons with severe disabilities and (2) quality indicators of communication services, which provide guidelines for evaluating service delivery systems.

10. Using Action Research to Promote Inclusive Schooling: Collaborative Innovations Project
Facilitated by Dr. Christine Salisbury, Principal Investigator, Collaborative Innovations Project
This session gave an introduction to the manner in which action research is being used in two school districts to address implementation issues related to inclusive schooling.

D. Concurrent Presentations, Session 4
Wednesday, November 9, 1994, 9:00 - 10:00 a.m.

1. Ski*Hi Intervenor Model
Facilitated by Dr. Linda Alsop, Project Director, Deaf-Blind Services
This session described the Utah Intervenor Project, which provides home-based early intervention services to young children who are deaf-blind and to the families of these children.

2. ABLE Inservice Project: Interactive Technology as an Inservice Training Medium
Facilitated by Dr. Susan M. Bashinski, Project Coordinator, ABLE Inservice Training
This session presented results of the pilot field study of a stand-alone, self-directed, hypermedia inservice training package for education workers to provide intervention to students who have severe disabilities.

3. "You and Me"
Facilitated by Dr. Robin Greenfield, Project Director, Idaho Project for Children and Youth with Deaf-Blindness
This presentation introduced the first in a series of five videos on the education of an 11 year old boy named Riley, who is totally blind, suffers profound hearing loss, and attends his neighborhood school. The "You and Me" series focuses on the people who support Riley and their process of educating him.

4. Systems Change in Oklahoma
Facilitated by Dr. Julie Hightower, Project Director
This session discussed the collaboration between the Oklahoma State Department of Education, the UAP of Oklahoma, and the Oklahoma Commission on Children and Youth to implement supportive education in a least- restrictive environment.

5. Critical Skills for Collaborative Change: Enabling Groups to Succeed
Facilitated by Mr. Tom Justice, Management and Organizational Development Consultant
During this two-hour session, Mr. Justice presented information on critical consultation and facilitation skills which collaborative groups need to succeed.

6. The Utah Wheel: A Model of System Change for Children and Families
Facilitated by Dr. John Killoran, Education Specialist, Utah State Department of Education
Dr. Blaine Seamons, Project Director, Utah Services to Children and Youth who are Deaf-Blind
Dr. Cathy Nelson, TA Specialist, Utah State Department of Education
Dr. Richard Mulholland, Western Region Coordinator, TRACES
Dr. Paddi Henderson, Western Region Assistant Coordinator, TRACES
This session presented a model of system change resulting in collaborative services and support for children with deaf-blindness (DB) and for the families of these children, detailing state and project initiatives which have increased the quantity and quality of services and resources available to DB children.

7. Consortium Research Institute on Social Relationships
Facilitated by Dr. Luanna Meyer, Director, Consortium for Collaborative Research on Children's Social Relationships
This session described a Constituent Group process to design and carry out "natural" interventions in classrooms, to promote positive relationships among students, families and educators, in contrast to "professional special education" interventions.

8. MOSAIC: Model Opportunities for Students to Attend Inclusive Classrooms in Pittsburgh
Facilitated by Dr. Barbara Minzenerg, Project Coordinator
Dr. Marie Hinchliffe, Special Education Supervisor
Dr. Cecelia Belasco, Inclusion Facilitator
This session introduced MOSAIC, an inclusive preschool project in which all students are full members of developmentally appropriate programs in the urban setting of Pittsburgh.

9. Maryland Least Restrictive Environment/Neighborhood Inclusion Project
Facilitated by Dr. Jerry White, Project Director
Dr. Carol Quirk, Project Manager, Maryland Neighborhood Inclusion Project
The Maryland Project promotes inclusive education through systems change strategies. Different Maryland counties are invited to participate, based on geography, leadership within the county, the resources the county is willing to commit to the project, and the county's commitment to the systems change.

E. Concurrent Presentations, Session 5
Wednesday, November 9, 1994, 10:15 - 11:15 a.m.

1. Project INSITE
Facilitated by Dr. Don Barringer, Director, Ski*Hi Institute
This session described the INSITE (In Home Sensory Impaired Family Early Intervention Serving Children with Sensory Impairments) program, including its philosophy, usefulness, resources, and training and implementation strategies.

2. A Bridge or a Barrier: the Results of a Study Group on School-Based Intervenors for Students with Deaf-Blindness
Facilitated by Dr. Robbie Blaha, Educational Consultant, Texas 307.11 Project
This session reviewed the activities of a group composed of local educational staff, human service agency staff, and parents, that met to discuss the appropriateness of the Intervenor Model in educational settings and to review a model of implementation proposed by the 307.11 staff in Texas.

3. The Utah Model Inservice Project for Professionals Serving Secondary Students with Severe Disabilities
Facilitated by Dr. Connie Mathnot-Buckner, Project Director
This presentation described the outreach efforts of the Project, which include establishing cross-age regional model demonstration sites, designing training modules using new technology, implementing cohort training of middle and high school teams and of transition teams, and coordinating with the Utah State Office of Education.

4. What's Happening for Families at the National Level
Facilitated by Ms. Sue Ferguson, Outreach Coordinator, NICHCY; Chairperson, National Coalition of Parent Involvement in Education (NCPIE)
Dr. Lucy Watkins, Education Advocate, Center for Law and Education
This presentation discussed how Goals 2000, ESEA, and the Family Involvement Partnership affect families who have children with disabilities.

5. Vermont Statewide System Support Project for Students with Severe Disabilities and Their Families
Facilitated by Dr. Timothy Fox, Project Coordinator
This presentation discussed the essential elements for restructuring schools to create caring communities of learners and to support the inclusion of all children in general education.

6. Center for Minority Special Education
Facilitated by Dr. Reginald Jones, Director, Center for Minority Special Education, Hampton University
This session described the work of the Center for Minority Special Education, which helps historically black colleges and universities, with an enrollment of at least 25% minority students, garner special education grants.

7. An Outreach Model to Enhance Mastery Orientation, Independence, and Inclusion of Students with Physical and Multiple Disabilities
Facilitated by Dr. Robin Ellison, Curriculum Development Coordinator, Hood Center for Family Support
Youth with physical and multiple disabilities are often challenged by barriers that impede their development of personal mastery and self-destination. The TAKE CHARGE intervention model that has been implemented in New Hampshire seeks to overcome these barriers.

8. State Support for Goals 2000
Facilitated by Dr. Thelma Leenhouts, Office of Reform Assistance and Dissemination, Department of Education
The Goals 2000 legislative act envisions a new role for Federal, state, and local educators. This session described various leadership activities which department teams will undertake.

9. The National Information Center for Children and Youth with Disabilities (NICHCY)
Facilitated by Ms. Suzanne Ripley, Director, NICHCY
This session described the mission and activities of NICHCY, a national clearinghouse for information about special education services and technical assistance. NICHCY supplies information upon request through a variety of media, in American-English or Spanish, operates a toll-free, national information hotline, maintains an extensive information library, and employs information specialists, librarians, and specially trained staff to assist clients.

F. Concurrent Presentations, Session 6
Wednesday, November 9, 1994

1. Funding Category: State/Multi-State 307.11
84.025A - State and Multi-State Services Projects for Children with Deaf-Blindness and Optional Pilot Projects for Children with Deaf-Blindness
Facilitated by Dr. Charles Freeman, Acting Branch Chief, OSEP/DES
Dr. Vic Baldwin, Director, Teaching Research

2. Funding Category: System Change
84.086J - Statewide System Change
84.086V - Inclusive Schooling Practices
Facilitated by Dr. Christine Salisbury

Appendix 2: Pre-Conference and Post-Conference Survey Results

I. The Pre-Conference Survey

Before the 1994 State Networking Meeting on Severe Disabilities, the FRC surveyed state coordinators of severe disabilities to identify topics that should be addressed during the Meeting. Forty-eight state coordinators responded to the survey, and in planning the Meeting the FRC did everything possible to honor their recommendations. This appendix gives a concise account of the results of the two surveys.

Identifying Meeting Topics: Results of the Pre-Conference Survey of State Coordinators

The FRC asked state coordinators what topics the state coordinators would like to address during the Meeting. Most respondents suggested several very specific topics. For clarity and brevity, and to give a sense of the general nature of the responses, the FRC has grouped the state coordinators' replies under these headings, followed by the number of specific activities that were requested under each heading:

Transition from School to Work (27)
Vocational Education (18)
Inclusion (46)
Severe Disabilities (27)
Legislation and Federal Initiatives (25)
Systems Change (22)
Communicable Diseases and Infections (28)
Families (20)
Personnel (17)
Technology and Assistive Technology (24)
Behavioral and Emotional Disabilities (23)
Programming and Curriculum (14)
School Finance and Funding (21)
Higher Education (16)
School Outcomes (29)
Communication (17)
Technical Assistance (31)

Expert Colleagues

The FRC asked state coordinators to identify expert colleagues whose presence could benefit future networking meetings. The FRC compiled the respondents' recommendations into a list of 51 professionals from university, public, and private practice, which the FRC will consult in planning future networking meetings. A few examples of the professionals that were recommended include:

Lou Brown, University of Wisconsin-Madison, transition specialist
Reed Martin, J.D., Carle Center for Health Law and Ethics, Chicago, IL, specialist on legal aspects of education
Jennifer York, Dept. of Education Psychology, Institute of Community Integration, University of Minnesota
Dr. Beverly Rainforth, State University of New York-Binghamton, systems change and inclusion specialist
Blair Roger, inclusion specialist
Luanna Meyer, representative from regular education
Linda Burkhurt, assistive technology specialist
Maggie McLaughlin (school financing)

Meeting Formats

The FRC asked state coordinators which formats, whether large group presentations, panels, small focus groups, or small group discussions, they would find useful at the meeting. The respondents suggested the following formats:

Large group (4)
Large group and small focus groups (4)
Large group or small groups (2)

Panel and small groups (2)
Panel presentation (1)
Small groups (11)

Keynote Speakers

The FRC asked the state coordinators to recommend keynote speakers for the Conference, with the proviso that they recommend only those speakers that 1) they believed would be of interest to most Conference participants, and 2) they knew to be a good speaker before a large audience. The FRC compiled the respondents' recommendations into a list of 39 professionals from university, public, and private practice. Currently the FRC is corresponding with several of the professionals from this list to identify topics for future networking meetings. A few examples of the speakers who were recommended include:

Denise Stewart, Associate Director of South Atlantic Regional Resource Center, inclusion specialist
Colleen Wieck, systems change specialist
Norman Kune, inclusion specialist
Jonathan Koziel, equality issues specialist
Ian Pumpian, transition specialist
Judith Snow, specialist in inclusion and self-advocacy
Edwin Martin, Ph.D., National Center for Disabilities Service
Jack Kemp, United Cerebral Palsy
Lynn Beckman, expert on legal issues that affect education

Networking

The FRC asked the state coordinators to suggest ideas about how to optimize networking opportunities at the Conference. The respondents put forth twenty-nine ideas, a few of which are given below:

Seat size-alike state groups together.
Arrange lunch tables by topic.
Conduct topic "corners" during breaks.
Build in small group "cracker barrels" to meetings with facilitators.
Allow participants to choose areas of interest prior to the meeting. The networking could result from planned activities for the focus groups.

Poster session

The FRC asked the state coordinators if they would be willing to participate in a poster session, and received these replies: YES: 16; NO: 26; No Response: 3. Some respondents gave additional comments pertaining to a poster session:

Yes — Have a session on Mobility Opportunities via Education Implementation and results in Florida.
Yes — Have a session relating to education reform impact on students in Kentucky with severe disabilities.
Yes — I would definitely attend a poster session, but I would not be able to present a poster session.
No — Due mainly to my lack of free time to put something together.
Yes — If notified about requirements ahead of time.

Discussions with OSEP staff

The FRC asked the state coordinators what topics they would like to discuss with staff from the Office of Special Education Programs, and received 48 replies, many of which fell under one of five topics:

(6) Reauthorization
(12) Federal priorities
(3) Goals 2000
(7) Current/new legislation
(2) Assistive technology

The FRC asked the state coordinators what format should discussions with OSEP staff follow, and received 32 replies, the majority of which fell into three categories:
(5) Large group
(9) Large group and small focus groups
(12) Small groups

Other suggestions

The FRC asked the state coordinators for other suggestions to ensure a useful, productive conference, to which the respondents responded with many comments and ideas, a few of which are given below:

Have funding as a topic.
Assistive devices would be an interesting subject.
Focus on innovative curricula, such as M.O.V.E.
Let's take an integrated approach to this meeting by having Richard Riley participate and/or at least have him invite each state to send their state commissioner or a ranking state regular education delegate.
The format and speakers for the 1992 conference were excellent.
At the 1993 NASDSE Annual Meeting, they offered an opportunity to learn about National Technical Assistance Projects such as NEC*TAS and NCEO. This type of information on severe disabilities would be very helpful.
I know that the regional resource centers have been working on numerous topics. A list of resources/contact persons by topical areas generated through the RRCs' efforts would be helpful.

II. The Post-Conference Survey

At the end of the conference, the FRC surveyed state coordinators of severe disabilities to gauge the success of the conference. Almost all the conference participants responded to this survey, the results of which will help define the objectives, format, and activities of subsequent conferences.

1. Please indicate the extent to which the conference met its objective of:
A. Exchanging information about promising practices demonstrating progress toward inclusionary practices for individuals with severe disabilities.
Very well 63% | Somewhat 33% | Not well 4% | Not at all 0%

B. Building skills for working with others, especially in my state, to promote best practices.

Very well 37% | Somewhat 48% | Not well 15% | Not at all 0%

C. Providing information to assist in efforts to promote promising practices in all areas related to services for individuals with severe disabilities.
Very well 48% | Somewhat 44% | Not well 8% | Not at all 0%

D. Networking with people from other states to share information, ideas, and activities related to serving individuals with severe disabilities.
Very well 74% | Somewhat 22% | Not well 4% | Not at all 0%

E. Discussing with others how to continue to exchange information to promote improved services for individuals with severe disabilities.
Very well 30% | Somewhat 52% | Not well 15% | Not at all 3%

2. Of the information, interactions, and materials you received during the conference, circle the one most significant thing you will take home.
A. Nice memories 7%
B. Information I will apply to my job 19%
C. Information I will share with my staff 52%
D. Information I will disseminate 22%

Please describe the information you will disseminate and the audience for whom you intend it.
Funding changes, service delivery changes. shared with local education agencies and regional services centers.
Material and information from several sessions.
Where's how appropriate inclusion is happening around the country? Can it happen in our states? I would disseminate to co-workers, parents, schools, administrators, etc.
The packet of articles — many are not yet published.
Transition/Fair Labor Standards.

3. How would you rate the following aspects of the conference?

Aspect	Rating	Excellent	Good/Fair	Very Poor
Pre-conference Information	33%	41%	22%	4%
Conference Organization	59%	26%	11%	4%
Presenters	41%	52%	7%	0%
Materials	52%	44%	4%	0%
Facilities	44%	41%	15%	0%
Food	48%	39%	9%	4%

Please comment on these aspects.
Materials given to us were great! I will share with others.

I like large group sessions mixed with smaller break-out sessions. Hearing reports on projects is good although most of these are also presented at other national conferences. In-depth tracking of a structured program change with action planning strategy session might be helpful.

This was one of the best conferences on deaf-blind I've ever attended.

Somewhat unclear about what "role" state coordinators were to play — next time bring "regular ed" stakeholders instead.

Federal presenters did not live up to expectations.

4. What recommendations do you have for planners of future meetings like this one?

There were too many concurrent sessions — having tracks or themes or panels encompassing several projects within 20-30 minutes gets more done, I think.

Please make future meetings more multi-dimensional. I didn't need an inclusion rally.

Repeat some concurrent sessions.

Include regular educators. Although we represent the "severe disabilities" contingency of education, a conference on inclusion should emphasize all students. I realize this could be a very large grouping but we must all hear the same things at the same time to really impact a "whole system change." I would have liked a list of all participants, especially State Coordinators, instead of just presenters.

Time in group with coordinators to discuss issues.

Think "inclusive" in terms of presenters. There was not equal representation of women and minorities in keynotes and general sessions. For example, there were three moms on a parent panel, and three white males on a state leadership panel.

Include regular educators and more parents as participants and audience members.

Set aside more time for breakout sessions.

Enjoyed meeting others from across the nation. Would have appreciated more unstructured time in which to talk and interact with them.

Include general education personnel.

Consider amount of paper handed out and ability to carry that home. Especially with so many bringing posters.

Session for sharing/networking with coordinators might be expanded. The short session was helpful, but additional sessions might be provided.

Send in questions for federal people prior to meeting so they are prepared to respond.

There is a need to have participants at the conference who are not members of the "special education circle." If we are to get further down the road of inclusive education, attending to the need of diverse learners, we need to have more people from "regular" education.

State Coordinators Meeting on all three days — an hour session daily with facilitators. This would encourage the continuity of networking among the state coordinators.

5. What is your overall rating of the Severe Disabilities Conference?

Excellent 48% | Good 44% | Fair 8% | Very poor 0%

Please comment on the overall quality of the Conference.
As project director, I would say excellent.
I especially liked the opportunities structured for networking.
I appreciate the effort to incorporate suggestions from the last meeting.
States need the support of meetings like this, especially those of us without universal support. Please keep it up, but expand focus on severe disabilities.
As a new participant, I was pleased to get information about projects and to network with colleagues.

6. If invited, would you come to this conference next year?
Yes: 100% | No: 0%

7. Would you recommend attending this conference if federal funding were NOT available?

Yes: 85% | No: 8% | No Response: 7%

8. Anything else?
The materials that were handed out were excellent. Really needed. Great conference, one of the best I've attended.
Include regular education people as participants. Include more parents (not just parents of deaf- blind).
What I have learned from this meeting is excellent. I need to attend this same conference in the future if there is a chance to attend. I'm working directly with students who have severe disabilities.
It's been a wonderful sharing experience.
To be honest, I'm not sure what I want from this meeting other than the federal perspective. I'm not disappointed in the content because I've learned/gained at least one thing from every session that I will use/disseminate/promote through my position. If I cannot define what I need or want, you can only be expected to provide something meaningful. You have done that and I appreciate your efforts and the opportunity to participate.
I needed this chance to discuss some crucial issues, and I'm walking away with some useful information and a broadened perspective.
You should model inclusion and include all disability groups.

I sincerely appreciated the opportunity to participate. I would have enjoyed more time with U.S. Department of Education staff.
Chose keynoters carefully. Just because someone is disabled doesn't mean the message given will be very useful, for example, "I've capitalized on my disability by starting my own consulting firm." Bring in a consumer who has battled the field and succeeded, such as Mary Somosa, Oberti, Holland, Mavis.
The State Fair idea was good, but be careful. Having one state highlight its segregated schools for the blind and deaf does not support inclusion.
This conference offered state coordinators an opportunity to explore current research/issues in their state as well as in others. In my state, I work closely with a university involved in systems change grants, and being here I've come to recognize how fortunate I am to have the relationship I do with this university, but I'm also aware of how other state coordinators don't have this, and how useful it would/can be. This conference offered an opportunity for us all to see what good things we're doing — and what issues lie ahead.
Although it was informative, the meeting was too political. I leave with the sense we weren't talking about how to move the agenda for kids with severe disabilities forward, but how do we preserve existing programs, especially the deaf-blind program.

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